

# Medical Science

25(117), November, 2021

## To Cite:

Alsaad A, Alramadhan N, ALjumah M, Alghareeb F, Alghadeer H. The effect of the parents' anxiety and depression on the quality of life of children with cerebral palsy in Al Ahsa, Saudi Arabia. Medical Science, 2021, 25(117), 2778-2788

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## Peer-Review History

Received: 19 September 2021

Reviewed & Revised: 20/September/2021 to 24/October/2021

Accepted: 25 October 2021

Published: November 2021

## Peer-review Method

External peer-review was done through double-blind method.

# The effect of the parents' anxiety and depression on the quality of life of children with cerebral palsy in Al Ahsa, Saudi Arabia

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## ABSTRACT

**Objective:** This study aims to test whether or not the parental depression and anxiety will affect the quality of life of children with Cerebral Palsy (CP) in Alahsa, Saudi Arabia. **Method:** This is a case control observational study, carried out in two study groups in Alahsa. The first group included parents of children with CP and the second group includes parents of typical children. Parental depression and anxiety assessed through The Patient Health Questionnaire (the Arabic version), using Depression modules, and generalized anxiety. QOL of the CP children assessed through the Pediatric Quality of Life Inventory cerebral palsy module (the Arabic version), and for typical children, translated Generic Core Scales have been used. **Result:** 80% of parents of CP children have depression and anxiety, and 66.6% of parents of typical children have depression and anxiety. There was no significant relationship between parental anxiety and depression with QOL of children with CP, although there is a significant relationship with movement and balance dimension. **Conclusion:** This study emphasizes that there was no significant relationship between parental anxiety and depression with QOL of children with CP.

**Keywords:** Cerebral palsy, quality of life, anxiety, depression.

## 1. INTRODUCTION

Cerebral palsy (CP) is a group of non-progressive neurodevelopmental disorders that lead to a permanent effect on a child's abilities of movement, maintaining balance and keeping posture (Bartels et al., 2020). These disorders are starting in early life and persisting through it (Rosenbaum et al., 2007). CP is due to damage in the fetal or infant's brain and associated with intellectual, learning disabilities, vision and hearing problems (Rosenbaum et al., 2007). The global incidence of cerebral palsy is between 2 and 3 per 1000 live birth (Forni et al., 2018). In Saudi Arabia, the estimated prevalence rate of children



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with CP is 23.4/10 000 (Al Salloum et al., 2011). Parents of children with CP have a higher prevalence of depression and anxiety compared to parents of typical children (Barreto et al., 2020). In Saudi Arabia, one study showed that 6% of mothers of children with CP had severe depression, and 21.6% had severe anxiety (Soliman et al., 2019). There are several predisposing factors that make the parent's who have children with CP at greater risk of developing mental illness to mental illness that include the severity of the disorders, the long duration of care, (Barreto et al., 2020) low socio-economic status, cultural and educational levels (Altindag et al., 2007).

Taking care of children with CP affects parents' psychological health that leads to decrease quality of life (QOL) of children with CP (Soliman et al., 2019) that include physical functioning, emotional functioning, social functioning, and school functioning in some studies with different variation (Mohammed et al., 2016). Depressed mothers of a child with CP were found to be less responsive, difficult to control negative mood, poor problem-solving skills that lead to unfavorable situations of children with CP, and poor quality of life (Murphy et al., 2011).

In Alahsa, Saudi Arabia, there are no sufficient studies that focus on the effect of parental anxiety and depression on the quality of life of a child with CP. This study aims to find out the correlation between parental anxiety, depression and the quality of life (QOL) of children with CP.

## 2. METHODS

### Study design

This is a case-control observational study.

### Setting

This study was conducted in Alahsa, Saudi Arabia. Study duration from 8/2020 to 6/2021.

### Participant

The study included two groups, the first group included parents of children with CP and the second group included parent of typical children in which the children in both groups aged 8-12 years old.

### Inclusion criteria

Parent with children with CP and parent of typical children aged 8-12.

### Exclusion criteria

Parents of CP children

Parent with history of psychological disorders before having children

Children aged less than 8 or more than 12.

Parents of typical children:

Children who are diagnosed with a chronic disease, or physical or mental disability

For both: Not the primary parent of the child (based on the hours of case provided, permanent residence with the child)

### Variables

In this study, the dependent variable was parental anxiety and depression, and the independent variable having a child with CP.

### Data sources and mangement

The sample from group one was collected from the local rehabilitation centers in Al Ahsa (childs' will center, Middle Eastern daycare), and Maternity and Children hospital at alahsa, Saudi Arabia. The sample from group two has been collected through an online survey, in which all questions were mandatory to be answered before submission to avoid missing data. There is a specific code for each participant for storage data that is secured by a password.

Parental depression and anxiety were assessed, through the Arabic version of The Patient Health Questionnaire (PHQ), Depression modules (PHQ9) have 9 items, and generalized anxiety (GAD7) has 7 items. The internal consistency reliability was determined by using Cronbach's alpha for the Arabic versions of PHQ9 and GAD7. The results were 0.857 and 0.763 respectively (Al Hadi et al., 2017). To assess the QOL of the CP children, Arabic versions of the Pediatric Quality of Life Inventory cerebral palsy module have been used, its Sensitivity was demonstrated among children with different diagnostic categories and

gross motor function, and Cronbach's alpha was measured and the result was =0.79. For typical children, Generic Core Scales (Peds QL) have been used. It has well-documented reliability and validity in the pediatric field, with Cronbach's alpha = 0.90. Parent proxy-report will be used which consists of 23 multidimensional items (Physical, Emotional, Social, School) (Varni et al., 2006 and 2001).

#### **Bias**

The sample from control group has been collected through an online survey using 6 different data collectors to eliminate any potential bias of data collecting. The samples from the case group were selected randomly from the registration office of the hospital and the centers according to the matched criteria.

#### **Study size**

According to the formula  $k=n_2/n_1=1$ ,  $n_1=((\sigma_1^2+\sigma_2^2/K) (z_{1-\alpha/2}+z_{1-\beta})^2)/\Delta^2$ . The study conducted in sample size of at least 30 participants (15 from each group).

#### **Statistical method**

The data have been collected and analyzed using a statistical package for the social sciences (SPSS) version 23. Quantitative variables are presented as frequencies and percentages. Mean and standard deviation were used for age, depression, anxiety, and quality of life scales. Pearson correlation was used to test the correlation between parental depression, anxiety, and the children's QOL. Chi-square, Mann-Whitney test was used to test the trigger factors of depression and anxiety. Mann-Whitney test was used to compare the mean of depression and anxiety scores between parents from the two groups. In comparing Quality of life scores in children from both groups,  $p<0.05$  value was considered statistically significant. Additionally, with 95% confidence interval was reported.

#### **Expected benefits**

We expect that QOL of Children with CP would be decreased as a consequence of parental anxiety and depression. Their quality of life can be improved by giving psychological support and monitoring the mental health of their parents.

#### **Ethical considerations**

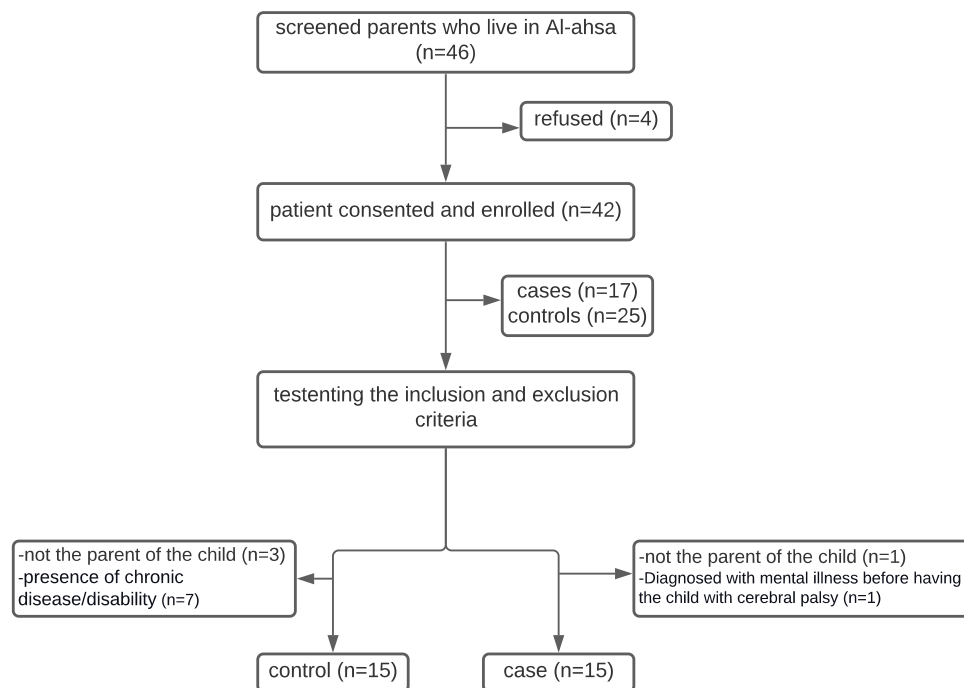
This study has been approved by the Research Ethics Committee of the King Fahad medical city in Riyadh, Kingdom of Saudi Arabia (20-504E) and consent have been taken from each participant.

### **3. RESULT**

A total of 46 individuals participated in the study; 16 were excluded due to the presence of one of the exclusion criteria. 4 Disagree with participating in the study, 4 of the responders were not the parent of the child, one parent was diagnosed with mental illness before having the child with cerebral palsy, and 7 children excluded from the typical children sample due to the presence of chronic disease/disability. Figure 1 shows the Study flow diagram. Of the 30 participants, 15 were parents of children with CP and 15 were parents of typical children.

#### **Socio-Demographic and family characteristics**

The Socio-Demographic data and family characteristics of both groups are illustrated in table 1. There were no differences between the study group and the control group in terms of the Socio-Demographic data and family characteristics ( $p\text{-value}>0.05$ ).



**Figure 1** Study flow diagram

<b>Table 1</b> Sociodemographic data and family characteristic and the differences between groups.				
Variables		Frequency (%) Total 30 (100%)		P-value*
		CP child 15	Typical child 15	
Gender of the child	Male	13 (86.7%)	9 (60%)	0.75
	Female	2 (13.3%)	6 (40%)	
Relationship with the child	Mother	6 (40%)	14 (93.3%)	0.20
	Father	9 (60%)	1 (6.7%)	
Age of mother	Less than 17 years	0	0	0.51
	Between 17-30 years	6 (40%)	6 (40%)	
	Between 31-45 years	9 (60%)	9 (60%)	
	More than 45 years	0	0	
Age of father	Less than 17 years	0	0	0.53
	Between 17-30 years	1 (6.7%)	0	
	Between 31-45 years	14 (93.3%)	11 (73.3%)	
	More than 45 years	0	4 (26.7%)	
Marital status of caregiver	Married	14 (93.3%)	15 (100%)	NA
	Divorced	1 (6.7%)	0	
	Widowed	0	0	
Child mainly lives with	Both Parents	14 (93.3%)	15 (100%)	NA
	Mother	1 (6.7%)	0	
	Father	0	0	
Residence in Al-Ahsa	Alhufuf	6 (40%)	7 (46.7%)	0.56
	Almubarraz	4 (26.7%)	7 (46.7%)	
	Aloion	5 (33.3%)	1 (6.7%)	

Hours spend with child during the day	Less than 6 hours	2 (13.3%)	7 (46.7%)	0.31
	Between 6-12 hours	2 (13.3%)	1 (6.7%)	
	Between 12-18 hours	7 (46.7%)	1 (6.7%)	
	More than 18 hours	4 (26.7%)	6 (40%)	
Educational level of the mother	Illiterate	0	0	0.22
	Primary school	2 (13.3%)	0	
	Secondary school	0	0	
	High school	4 (26.7%)	1 (6.7%)	
	University	9 (60%)	14 (93.3%)	
	High degree	0	0	
Educational level of the father	Illiterate	1 (6.7%)	0	0.25
	Primary school	0	0	
	Secondary school	0	0	
	High school	6 (40%)	4 (26.7%)	
	University	7 (46.7%)	8 (53.3%)	
	High degree	1 (6.7%)	3 (20%)	
Household size	3	3 (20%)	0	0.48
	4-6	10 (66.7%)	13 (86.7%)	
	More than 6	2 (13.3%)	2 (13.3%)	
Number of children below 14 years in the family	1	6 (40%)	2 (13.3%)	0.68
	2	3 (20%)	4 (26.7%)	
	3	2 (13.3%)	4 (26.7%)	
	Equal or more than 4	4 (26.7%)	5 (33.3%)	
Family Income level	Less than 3500 SR	4 (26.7%)	0	0.52
	Between 3500-6000 SR	2 (13.3%)	1 (6.7%)	
	Between 6000-10000 SR	3 (20%)	7 (46.7%)	
	Between 10000-150000 SR	5 (33.3%)	4 (26.7%)	
	More than 15000 SR	1 (6.7%)	3 (20%)	

NA, statistical test not available as too few participants in one of the categories

\* $\chi^2$  test was used to compare between the groups.

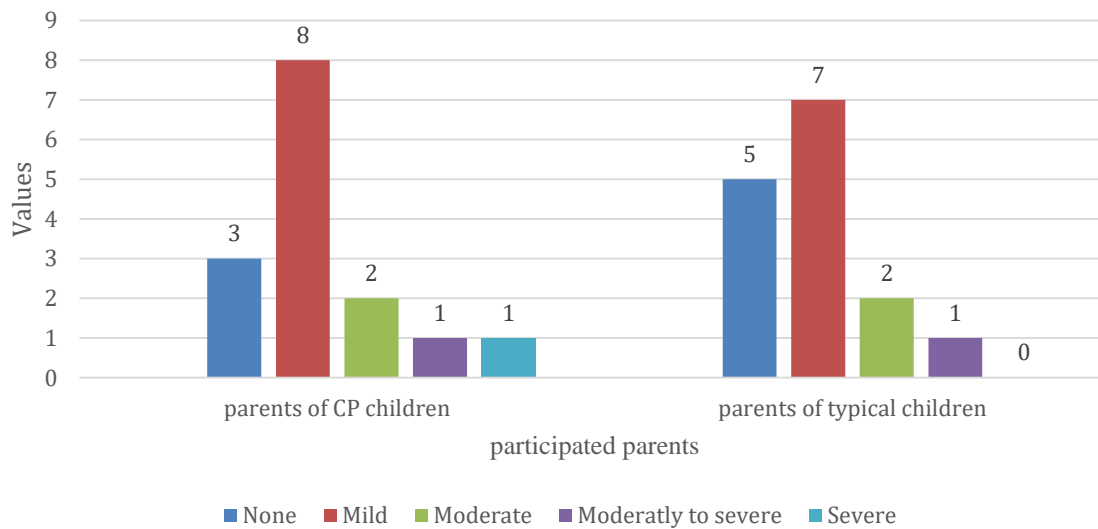
### Depression and anxiety among the studied parents

#### Prevalence of depression and anxiety among the studied parents

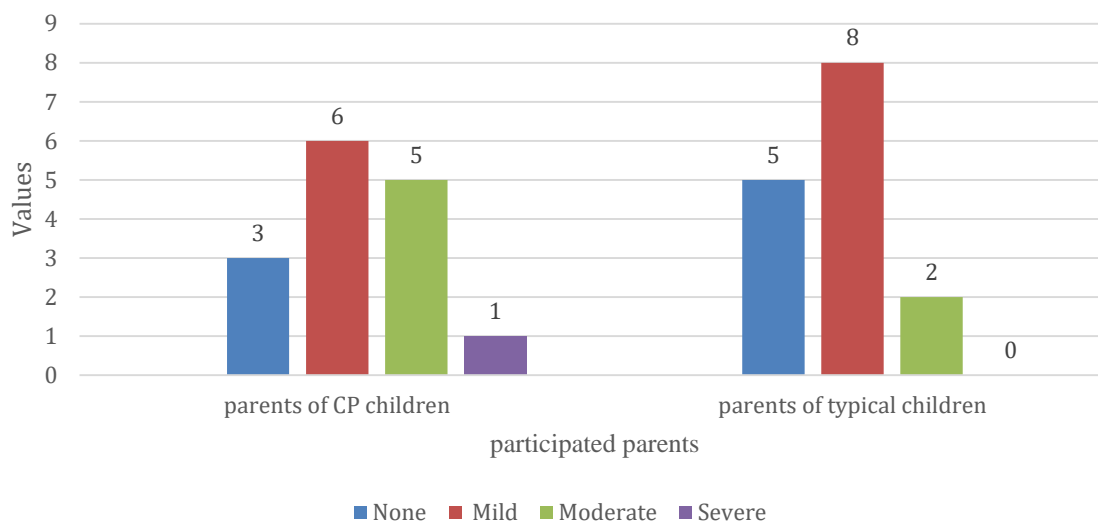
80% of parents of CP children have depression and anxiety, and 66.6% of parents of typical children have depression and anxiety.

#### Score and severity of the depression and anxiety among the studied parents

The depression being scaled from 0 to 27, the mean score of depression in parents of CP children was 8.47 (SD=5.235), and the mean score of their anxiety was 8.27 (SD=4.415). On the other hand, the mean score of depression in parents with typical children was 6.67 (SD=4.304), and their mean score of anxiety was 6 (SD=3.982). Figure 2 & 3 illustrates the severity of depression and anxiety in each group. Using the Mann-Whitney test, there was no significant difference between the mean of depression and anxiety scores between the groups, in which the p-value was 0.31 and 0.11, respectively.



**Figure 2** Depression severities among participated parents



**Figure 3** Anxiety severities among participated parents

#### Impact of the depression and anxiety on the parents' life

Table 2 illustrate the impact of depression and anxiety on the Parents' life. Pearson's  $\chi^2$  test showed that there is a significant difference between the impact of depression and anxiety on each group (p-value is 0.021 and 0.023 respectively) in which Depression and anxiety have a greater impact on lives of parents with cerebral palsy children.

<b>Table 2</b> Depression: How difficult was it that the previous problems caused you when performing your work, studies, carrying out your responsibilities in your home, or getting along with people?				
	There is never any difficulty	Rather difficult	Very difficult	Unbearably difficult
CP parents	5 (33.3%)	5 (33.3%)	3 (20%)	2 (13.3%)
Typical parents	10 (66.7%)	5 (33.3%)	0	0
Anxiety: How difficult was this problem for you when performing your work, studies, carrying out your responsibilities in your home, or getting along with people				
CP parents	2 (13.3%)	1 (6.7%)	9 (60%)	3 (20%)
Typical parents	10 (66.7%)	5 (33.3%)	0	0

**Analysis of the Relationship between Factors Linked to the intensity of Anxiety and Depression on the participated parents**

The bivariate analysis of the factors associated with parental anxiety and depression with cerebral palsy and typical children is shown in table 3. There was a significant relationship between depression in parents with cerebral palsy children and gender of the child (P value= 0.030), in which parents of male children have higher severity of depression and age of the father (P-value = 0.005) in which most of the fathers who have depression are from the middle age group (Between 31-45 years). Furthermore, there was a significant relationship between anxiety in parents with typical children and the gender of the child (P value= 0.003). In regards to Parents Satisfaction with the services provided for their children with CP. It is illustrated in table 4; there was no significant correlation between Parents Satisfaction with the services and the parental anxiety and depression with cerebral palsy (p-value >0.05).

**Table 3** Factors linked to the intensity of depression and anxiety for both groups.

Factors	P-value <sup>1</sup>			
	depression		anxiety	
	Parents of CP children	Parents of typical children	Parents of CP children	Parents of typical children
Gender	0.030*	0.126	0.834	0.003*
Relationship	0.421	0.543	0.343	0.343
Marital status of caregiver	0.369	NA	0.658	NA
Residence in al-ahsa	0.444	0.328	0.342	0.403
factor	p-value <sup>2</sup>			
	depression		anxiety	
Age of mother	0.353	0.126	0.644	0.335
Age of father	0.005*	0.101	0.543	0.092
Hours spend with child during the day	0.506	0.703	0.902	0.613
Educational level of the mother	0.365	0.543	0.226	0.343
Educational level of the father	0.827	0.220	0.447	0.609
Household size	0.094	0.883	0.740	0.777
Number of children below 14 years in the family	0.715	0.076	0.148	0.129
Family income level	0.882	0.283	0.283	0.497
Factor	Frequency (%)		p-value <sup>1</sup>	
			depression	anxiety
Presence of Complications	No	4 (26.7%)	0.13	0.86
	Yes	11 (73.3%)		
Number of Complications	No Complications	4 (26.6%)	0.13	0.60
	1 Complication	3 (20%)		
	2 or more Complications	8 (53.3%)		
Types of Complications	Sight	3 (9.4%)	NA	NA
	Hearing	5 (15.6%)		
	Speech	7 (21.9%)		
	Swallowing and feeding	7 (21.9%)		
	Convulsions	4 (12.5%)		
	Mental	6 (18.8%)		

	developmental			
Another child with CP	No	15 (100%)	NA	NA
	Yes	0		
Health insurance	No	13 (86.7%)	0.73	0.32
	Yes	2 (13.3%)		
Getting help from others	Yes	13 (86.7%)	0.06	0.83
	No	2 (13.3%)		
emotional support provided from family	Poor	4 (26.7%)	0.28	0.79
	Accepted	7 (46.7%)		
	Good	4 (26.7%)		
Do you think you have a hand in your child's illness?	No	13 (86.7%)	0.71	0.83
	Yes	2 (13.3%)		
Do you think that your knowledge of your child's illness may contribute to improving your quality of life and that of your child?	Yes	15(100%)	NA	NA
	No	0		

Chi-square coefficient used

Spearman rank correlation coefficient used

NA, the statistical test was not available as too few participants in one of the categories.

**Table 4** Satisfaction of services provided to child CP

	Speech therapy	Occupational therapy	Physical therapy	Medical advices when needed
Extremely dissatisfied	5 (33.3%)	4 (26.7%)	5 (33.3%)	2 (13.3%)
Dissatisfied	2 (13.3%)	3 (20%)	2 (13.3%)	2 (13.3%)
Natural	3 (20%)	4 (26.7%)	2 (13.3%)	8 (53.3%)
Satisfied	3 (20%)	4 (26.7%)	5 (33.3%)	2 (13.3%)
Extremely satisfied	0	0	0	1 (6.7%)
Does not need this service	2 (13.3%)	0	1 (6.7%)	0

### Quality of life of the studied children

The QOL score of children with CP being scored from 0 to 3900, the mean was 1250 (SD=727.8). On the other hand, the QOL score of typical children being scored from 0 to 2300. The mean score of QOL of typical children was 1956.67 (SD=277.4) in which a higher number indicates a better QOL. Using the Mann-Whitney test; there was a significant difference between the mean of QOL of typical children and QOL of children with CP (p-value=0.00) in which typical children have a higher score of QOL.

### QOL dimensions

As each QOL dimension have a different number of items and scores, each dimension is converted into a percentage to facilitate comparison between them; table 5 illustrates the QOL dimensions of both groups. Regarding the QOL of children with CP, the school performance dimension has the lowest mean of the score (mean= 7.3%), including the children who have attended school activities only. Followed by daily activity (mean=28.8%), and the highest was the pain dimension (mean=54.1%). On the other hand, emotional functioning has the lowest mean score in QOL dimensions in the typical children (mean=80.3%), and the highest was social functioning (mean=91%).



**Table 5** QOL dimensions: QOL dimensions of Children with CP

	Daily activity	School performance	Balance and Movement	Aches and Pain	Fatigue	Eating	Speech and communication
N	15	11	15	15	15	15	15
mean	28.3%	7.3%	46.4%	54.1%	51.2%	33.3%	30.8%
SD	32.2%	17.1%	32.7%	31.1%	28.4%	31.1%	29.2%
minimum	0%	0%	0%	0%	0%	0%	0%
maximum	92%	56.2%	100%	100%	100%	100%	100%
QOL dimensions of Typical children							
	Physical functioning		Emotional functioning	Social functioning		School functioning	
N	15		15	15		15	
mean	84.5%		80.3%	91%		84.6%	
SD	12.8%		19.5%	13.6%		12.8%	
minimum	31.2%		35%	65%		65%	
maximum	100%		100%	100%		100%	

#### *Correlations between parental anxiety and depression and QOL of typical children and its dimensions*

Using chi-square test, there was a significant relationship between parental anxiety and depression and QOL of typical children; the P-value is 0.014 and 0.004, respectively. Regarding the correlation of parental anxiety and depression and each dimension, using the Pearson correlation coefficient, there was a significant relationship between parental anxiety and social functioning (p-value = 0.003  $r_s=-0.7$ ), with school functioning (p-value = 0.020  $r_s=-0.6$ ), with emotional functioning (p-value = 0.012  $r_s=-0.6$ ). Negative results of the correlation coefficients ( $r_s$ ) indicate the inverse relationship

#### *Correlations between parental anxiety and depression and children with CP QOL and its dimensions*

Using chi-square test, there was no significant relationship between parental anxiety and depression with QOL of their children, in regards to the correlation of parental anxiety and depression and each dimension. Using Pearson correlation coefficient, there is a significant relationship between parental depression and movement and balance dimension (P value = 0.023,  $r_s=-0.5$ ).

## 4. DISCUSSION

In this study, we mainly assessed the effect of the parents' anxiety and depression on the QoL among CP patients in comparison to typically developed children. A review of the related literature and published findings show that CP children parents have a higher prevalence of depression and anxiety than parents of typical children, with depression being the most studied and determined disorder (Barreto et al., 2020). The present study results appear to agree with the previous studies in which 80% of CP children parents reported different degrees of depression and anxiety. In comparison, it was 66.6% in parents of typically developed children. These findings may be explained by that children with CP need special care of frequent medical visits and home care. Furthermore, CP parents' mental health can be adversely affected by social stigma and discrimination against children with disabilities in the society (Soliman et al., 2019). Moreover, the present study found that depression and anxiety prevalence are higher than that observed in other studies. One of the previous studies done in Al-Taif city, Saudi Arabia has found that 55.1% of mothers of children with CP have depression and 69% have anxiety (Soliman et al., 2019). Two other studies conducted in Iran and Pakistan revealed that the percentage of depression was 71% and 49.3% respectively (Sousa et al., 2011; Ahmadizadeh et al., 2014).

In a previous study, the mean score of depression and anxiety for parents of typical children was  $4.98 \pm 2.99$  and  $5.58 \pm 3.76$  respectively; comparing to  $6.67 \pm 4.3$  and  $6 \pm 3.9$ . In our study that could be attributed to the COVID-19 pandemic in which a recent study has shown that there is an increase in rates of depression and anxiety in the period between the years 2018 and 2020 by 72.2% (Almansour et al., 2013; Bin Dhim et al., 2021). The results exhibit that age of the mother has a significant impact on many dimensions of QOL, including speech, communication, movement, balance, and eating; The younger the mother, the more positively it affects the children QOL of CP children. The variability of the results within different studies could be attributed to using different scales as an assessment tool of depression and anxiety. Additionally, the sample size has a major role in this

variability. Some studies assumed that parents' mental health affects their child's quality of life (Barreto et al., 2020; Mohammed et al., 2016).

In Saudi Arabia, one study showed that parents caring for children with CP affected their mental health condition, leading to decreased QOL of children with CP (Soliman et al., 2019). The findings from this study suggested that parental depression affects some dimensions of the quality of the life of children with CP such as movement and balance. Regardless of the age, a mother of a child with CP has a 2.26-time risk of developing depression (Soliman et al., 2019; Sajedi et al., 2010). Comparing to parents with typical children, there was significant relation between parental anxiety and other dimensions of QOL of children with CP. For example, when social functioning decreases, the severity of the anxiety increases, or vice versa. Additionally, children of younger fathers appeared to have a better emotional functioning.

Another significant issue was studying the trigger factors and their contribution to the severity of parental depression and anxiety. A study done in Saudi Arabia found that some factors influence parental mental health, including the severity of the health condition and caregiving time to the child with CP (Barreto et al., 2020). Another study conducted in turkey found that the disability level, socioeconomic status, cultural and educational levels all are contributing factors (Altindag et al., 2007). In the present study, the trigger factors of parental depression of a child with CP were the gender of the child and the age of the father. However, the trigger factors of parental anxiety with typical children were the gender of the child. In both CP and typically developed children, the male gender appears to be a predominant factor for parental mental health.

The limitations of this study were the small sample size that limits the statistical value of the findings and makes it difficult for generalization. However, this encourages us as researchers to direct the scope toward the parents with disable children and intervene early to improve quality of life and well-being. Additionally, the fact that the study was conducted during the COVID-19 pandemic; this could have affected the depression and anxiety prevalence. Furthermore, this study was conducted in one region of the whole Kingdom of Saudi Arabia. A further corporation within different regions is needed to improve or make a program for a parent with a child with a disability. Prospective studies are recommended to see pre-and post-psychological interventions.

## 5. CONCLUSION

This study demonstrated that parents of children with CP have poor psychosocial well-being compared with parents of typical children. These results suggest improving parental wellbeing through interventions is needed.

### Acknowledgment

We thank the participants who contributed samples to the study. Also we are gratefully acknowledged the support provided from Dr. Ali Jawad Alsaad, Child and Adolescent Psychiatry for his guidance and supervision and we are thankful for Dr. Ahmad N. Al Hadi, Dr. Fadwa, and the Mapi institute for giving the permission to use the Arabic version of the questionnaires

### Author contribution

Ali Alsaad: Supervision, Writing, review, and editing of the manuscript.

Narjes Alramadhan: Proposal writing, Data collection and data entry, Writing, and editing of the manuscript

Maryam ALjumah: Proposal writing, Data collection, Writing, review, editing of the manuscript

Fatimah Alghareeb: Proposal writing, Data collection, Writing, review, editing of the manuscript

Hussain A. Al Ghadeer: Proposal writing, Data collection and data entry, Writing, and editing of the manuscript

### Conflicts of interest

The authors declare that they have no conflict of interest.

### Funding

This study has not received any external funding.

### Data and materials availability

All data associated with this study are present in the paper.

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